



BILLING CODE: 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Advisory Committee on Heritable Disorders in Newborns and Children

Notice of Meeting

In accordance with section 10(a)(2) of the Federal Advisory Committee Act (Public Law 92-463, codified at 5 U.S.C. App.), notice is hereby given of the following meeting:

Name: Advisory Committee on Heritable Disorders in Newborns and Children

Dates and Times: February 11, 2016, 8:30 a.m. to 5:00 p.m.

February 12, 2016, 8:30 a.m. to 3:00 p.m.

Place: Webinar and In-Person

National Institutes of Health

45 Center Drive Room

Bethesda, MD 20892

Status: The meeting will be open to the public with attendance limited to space availability. Participants also have the option of viewing the meeting via webinar. Whether attending in-person or via webinar, all participants must register for the meeting. The registration link will be made available at <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/>.

The registration deadline is Friday, February 5, 2016, 11:59 PM Eastern Time.

Purpose: The Advisory Committee on Heritable Disorders in Newborns and Children (Committee), as authorized by Public Health Service Act, Title XI, § 1111 (42 U.S.C. 300b-10), as amended by the Newborn Screening Saves Lives Reauthorization Act of 2014 (P.L. 113-240), was established to advise the Secretary of the Department of Health and Human Services about the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In addition, the Committee's recommendations regarding additional conditions/heritable disorders for screening that have been adopted by the Secretary are included in the Recommended Uniform Screening Panel (RUSP) and constitute part of the comprehensive guidelines supported by the Health Resources and Services Administration. Pursuant to section 2713 of the Public Health Service Act, codified at 42 U.S.C. 300gg-13, non-grandfathered health plans and group and individual health insurance issuers are required to cover evidence-informed care and screenings included in the HRSA-supported comprehensive guidelines without charging a co-payment, co-insurance, or deductible for plan years (in the individual market, policy years) beginning on or after the date that is 1 year from the Secretary's adoption of the condition for screening.

Agenda: The meeting will include: (1) a panel discussion on Long Term Follow-up activities regarding newborns and children identified with a condition via newborn screening.

Presentations may include perspectives from state public health experts, researchers, and providers; (2) updates from workgroups focused on cost analysis in newborn screening, newborn screening timeliness, and pilot studies for future nominated conditions; and (3) a discussion on proposed priorities and action items from the three subcommittees (Laboratory Standards and Procedures, Follow-up and Treatment, and Education and Training) to develop a plan for 2016.

There are no votes that involve proposed additions of a condition to the RUSP scheduled for this meeting.

Agenda items are subject to change as necessary or appropriate. The agenda, webinar information, Committee Roster, Charter, presentations, and other meeting materials will be available on the Committee's website at

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Public Comments: Members of the public may present oral comments and/or submit written comments. Comments are part of the official Committee record. The public comment period is tentatively scheduled for both days of the meeting. Advance registration is required to present oral comments and/or submit written comments. Registration information will be on the Committee website at

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>. The registration deadline for public comments is Friday, February 5, 2016, 11:59 PM Eastern Time. Written comments must be received by the deadline of January 29, 2016, 11:59PM Eastern Time in order to be included in the February meeting briefing book. Written comments should identify the individual's name, address, email, telephone number, professional or business affiliation, type of expertise (i.e., parent, researcher, clinician, public health, etc.), and the topic/subject matter of comments. To ensure that all individuals who have registered to make oral comments can be accommodated, the allocated time may be limited. Individuals who are associated with groups or have similar interests may be requested to combine their comments and present them through a single representative. No audiovisual presentations are permitted. For additional information or questions on public comments, please contact Alaina Harris, Maternal and Child Health Bureau, Health Resources and Services Administration; email: aharris@hrsa.gov.

Contact Person: Anyone interested in obtaining other relevant information should contact Alaina Harris, Maternal and Child Health Bureau, Health Resources and Services Administration, Room 18W66, 5600 Fishers Lane, Rockville, Maryland 20857; email: aharris@hrsa.gov.

More information on the Advisory Committee is available at <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Jackie Painter,

Director, Division of the Executive Secretariat.

[FR Doc. 2016-01432 Filed: 1/25/2016 8:45 am; Publication Date: 1/26/2016]